

Applying Participatory Design Mixed-Methods Approaches to Refine Twitter-Based Social Support Interventions for African Americans and Hispanic Family Caregivers of Persons with Dementia

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Abstract. We applied mixed-methods to refine our first version of the Twitter message library (English 400, translated into Spanish 400) for African Americans and Hispanic family caregivers for a person with dementia. We conducted a series of expert panels to collect quantitative and qualitative data using surveys and in-depth interviews. Using mixed methods to ensure unbiased results, the panelists first independently scored them (1 message/5 panelist) on a scale of 1 to 4 (1: lowest, 4: highest), followed by in-depth interviews and group discussions. Survey results showed that the average score was 3.47, indicating good to excellent (SD 0.35, ranges from 1.8 to 4). Quantitative surveys and qualitative interviews showed different results in emotional support messages.

Keywords. Dementia caregiving, participatory design, social media

1. Introduction

Racial and ethnic minorities have higher prevalence of dementia in the US [1]. Moreover, dementia caregiving demands a higher, more intense level of care than other conditions [1]. Because of structural and socio-economic disadvantages, racial and ethnic minority dementia caregivers suffer more from social isolation, loneliness, poor health status, and poor quality of life [1]. Although virtual interventions to provide social and physical activity support, have become popular during the COVID-19 pandemic, what makes

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such an intervention effective remains largely unknown [2,3]. The expansion of social media use among underserved populations, particularly Twitter, can potentially provide social and physical support for underserved dementia caregivers [3]. However, analyzing Tweet data and social network structures remains a rather novel form of study, and Twitter has rarely been used as an intervention delivery tool in health [3].

Participatory design is a user-centered approach for developing technology-based interventions suitable for user characteristics [4]. A mixed method that combines quantitative and qualitative data collection and/or analyses to answer multifaceted research questions (e.g., focus group, survey, subjective and objective user observational usability test), has been commonly applied during the participatory design process [4]. Although the participatory design approach has been a common practice in the informatics field for the past two decades, little is known to involve older ethnic and racial minorities in the development design process [3, 4]. Therefore, the purpose of the study was to apply a participatory design mixed-methods approach to refine a Twitter-based intervention to enhance the social support (4 constructs: informational, instrumental, emotional, appraisal) for Hispanic and African American dementia caregivers [5].

2. Methods

We applied mixed-methods to refine our first version of the Twitter message library (English 400, translated into Spanish 400) for African Americans and Hispanic family caregivers for a person with dementia. We conducted a series of expert panels to collect quantitative and qualitative data using surveys and in-depth interviews. A total of seven experts—including four family caregivers of a person with dementia (two African Americans, one of whom was male and the other female, and two bilingual Hispanics, both female) and three health professionals (three neurology clinicians and one communication expert)—participated together in the expert panel discussions. The four caregivers were recruited from the caregiver registry and via flyers posted within and outside the institution. Eligible caregivers included those who were 18 years of age or older, had been a primary caregiver of a person with dementia for at least three years, spoke English or Spanish, and used text messaging. Eligible professionals included at least five years of experience and publication in dementia caregiving. An eligible health communication specialist included one with a degree in health literacy. All caregivers were adult children (aged 45 to 63) of individuals with dementia and varied educational backgrounds. Both neurological clinicians with 20 years of experience in taking care of dementia patients were recruited from the Department of Neurology at CUIMC via email, and a Hispanic health communication specialist with a doctorate was recruited through collaborators in New York City Hispanic Dementia Caregiver Research Program.

Panelists independently reviewed each Twitter message (instrumental 100, emotional 100, informational 100, appraisal 100 [5]) whether the message was understandable, useful and culturally sensitive. Using mixed methods to ensure unbiased results, the panelists first individually scored them (1 message/5 panelist) on a scale of 1 to 4 (1: lowest, 4: highest), followed by in-depth interviews and group discussions [4]. Each expert panel lasted approximately three hours, and caregivers voluntarily donated several more hours of their time after the expert panel. Descriptive statistics were used to summarize quantitative survey data, followed by content analysis for qualitative data. Expert panels were conducted in December 2020 via Zoom. Written consent was

obtained from the participants, and the study was approved by the Institutional Review Board (IRB).

3. Results

Survey results showed that the overall average score was 3.47, indicating good to excellent (SD 0.35, ranges from 1.8 to 4). Instrumental support messages (n=100, e.g., social works, Medicare/Medicaid, long-term care facility) received the highest score in its usefulness (3.67, SD 0.35) and fair score in the understandable category (3.47, SD 0.31). Informational support messages (n=100, e.g., diagnosis, signs and symptoms, treatment and clinical trials) received above-average scores (usefulness: 3.49, SD 0.30, easy to understand: 3.59, SD 0.29). Whereas most studies focus on mental health, emotional support messages (n=100) received the lowest grades in usefulness (3.19, SD 0.46) and understandability (3.30, SD 0.31). The lowest scores in the quantitative methods were noted as the opposite result from the qualitative assessment from the panelist discussion. Appraisal support messages (n=100, e.g., having someone to talk to) were noted as the easiest to understand (3.65, SD 0.18) yet somewhat less useful (3.39, SD 0.23) than instrumental or informational support messages (Figures 1, 2).

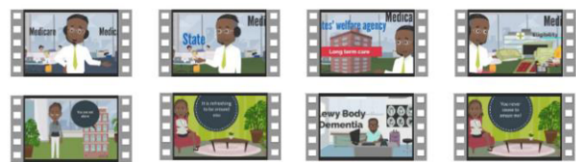


Figure 1. Screenshots of animated videos of Twitter-based interventions to enhance social support for African American and Hispanic family caregivers for a person with dementia



Figure 2. Expert scores on easy-to-understand and usefulness of 400 Twitter messages to enhance social support for African American and Hispanic family caregivers of a person with dementia (4 caregivers, two neurology clinicians, one communication expert)

4. Discussion and Conclusions

This study applied a participatory design mixed-methods approach using surveys and in-depth interviews through a series of an expert panels to refine a Twitter-based intervention to enhance the social support (4 constructs: informational, instrumental, emotional, appraisal) for Hispanic and African American family caregivers a person with dementia [4,5]. Based on the results of expert panels, we removed approximately one-tenth of non-useful messages from our Tweet message library and revised one-third of the messages the panelists identified as difficult to understand in the survey.

Surprisingly two-thirds of those requiring revision to make it easy were to provide emotional support rather than instrumental support (e.g., social work services, health system, insurance, access) or informational support (e.g., clinical trials, treatment, diagnosis, symptoms) Tweets which are knowledge and information-intensive [5]. Conversely, clinicians and caregivers verbally responded with favors to those emotional support messages during the in-depth qualitative interview (e.g., "This is it. I love all of the messages in this [emotional] section. This is what the caregivers need"). Future studies are needed to explore further the opposite results from the quantitative survey and in-depth qualitative interview on emotional support messages [2,3,5].

In terms of appraisal support messages, all panelists perceived the messages as easy to understand and useful except one family caregiving panelist whose occupation is a psychological therapist [5]. The panelist recommended revising the messages to provide more culturally sensitive to those with low self-esteem. Appraisal support is defined as having someone available to talk to about one's problems. It has been identified as a crucial determinant of coping and is highly effective in protecting people against the negative effects of stress [3,5]. On the other hand, appraisal support has been rarely explored in the family dementia caregiving domain, and our finding adds to the body of knowledge in appraisal support and dementia caregiving [5].

In terms of the cultural artifacts used in the evidence-based Tweet messages, which included music, quotations, culturally sensitive audio and imagery, all panelists strongly suggested increasing the number of animation videos to more than half of the messages to make the animation videos more vibrant (e.g., inserting more objects into the video and enhancing the movement of the objects) but to use quiet and soothing classical background music. Future studies on delivery modes, including the cost-effective animation production methods, are needed.

In conclusion, participatory design mixed-methods approaches with a series of expert panels were useful to refine Twitter-based social support interventions for African Americans and Hispanic family caregivers of persons with dementia. Our approach can be applied to caregivers with other chronic diseases and conditions.

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